CanNET
Cancer Service Networks National Demonstration
Project

The development of a consumer participation
strategy for CanNET Victoria

Final Report

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Acknowledgements

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Executive summary

The Cancer Service Networks National Demonstration Project (CanNET) is an initiative of Cancer Australia that aims to strengthen cancer care for people living in rural and regional Australia. CanNET has been developed in response to research that shows poorer cancer outcomes for people who live in rural areas.

CanNET Victoria is one of seven cancer service networks being developed across Australia, with a network being established in each state and the Northern Territory. CanNET Victoria is being undertaken in collaboration between the North Eastern Metropolitan Integrated Cancer Service (NEMICS) and the Hume Region Integrated Cancer Service (Hume RICS). CanNET Victoria is working to create a partnership between these two integrated cancer services that is productive and sustainable. This is focussed on strengthening the local delivery of cancer services in the Hume region and improving the care for those who receive aspects of their treatment at metropolitan cancer services. The project will run until June 2009.

This report is the final deliverable for the CanNET Victoria Consumer Participation project. It presents the findings from a series of group meetings and individual interviews with a total of 128 people affected by cancer. These consultations were designed to capture experiences of cancer care for people living in the Hume and North Eastern Metropolitan areas of Victoria and to guide CanNET planning and areas of focus. A further key objective was to inform the development of a consumer participation strategy for CanNET Victoria.

This project has identified a series of challenges faced by people affected by cancer, primarily across the Hume region of Victoria. It also provides a clear set of directions for project activities to address these challenges and to improve the experience of cancer care for consideration by the CanNET Victoria steering group.

A major challenge facing CanNET, in developing a consumer participation strategy, is the relatively short term nature of the project. However, the common imperative for ICS' in Victoria to incorporate effective consumer participation into their cancer services improvement work provides an opportunity to sustain the ground work laid by CanNET Victoria through the ICS'.

A consumer participation strategy is recommended that is designed to provide an effective means of achieving the goals of the CanNET initiative as well as providing a solid starting point for further consumer participation in longer term cancer services improvement. A register of 71 individuals has been established as a part of this project representing a very good starting point for this further work.

1. CanNET and consumer participation

A brief overview of CanNET Victoria, the broader Cancer Australia context and the consumer participation policy context is provided to set the scene for this report.

1.1. Commonwealth Government cancer reforms and CanNET

Cancer Australia has been established as a national agency providing leadership to improve the quality and coordination of cancer control, to ultimately improve outcomes for people with cancer and their families and to reduce the impact of cancer on our community.

CanNET is a key initiative of Cancer Australia focused on strengthening cancer care in regional Australia. It seeks to:

> *"improve outcomes and reduce disparities in outcomes for people affected by cancer by providing high quality, clinically effective and coordinated cancer services across Australia."* [1]

The CanNET model is drawn from the work of the NHS Scotland on Managed Clinical Networks defined as:

> *"linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professionals and Health Board boundaries, to ensure equitable provision of high quality clinically effective services throughout Scotland."* [2]

The focus of CanNET is on trialling the development of virtual organisations that span traditional geographic, professional and organisational boundaries to facilitate open access, communication and a responsive cancer services system. Key principles to underpin CanNET include the need for:
o Clarity about management arrangements
o A multidisciplinary and professional approach
o **Consumer input**
o Evidence-based practice
o Clinical audit
o Appropriate training.

Guiding concepts that must be incorporated into the planning processes for this project include:
o "Network" defined in a comprehensive way encompassing primary, secondary, tertiary public and private sector providers
o **Consumer involvement in service planning, review and evaluation**
o A focus on equity of outcome regardless of where an individual first presents
o The need to be providing services to a population of more than 500,000 people such that the virtual comprehensive cancer service has a critical mass
o Leadership and teamwork development
o Utilisation of telemedicine and information and communication technologies
o Making the best use of scarce specialist expertise.

Seven demonstration projects are being undertaken across Australia from February 2007 to May 2009. In Victoria, a successful application was made by the Hume Regional

Integrated Cancer Service (Hume RICS) and the North Eastern Metropolitan Integrated Cancer Service (NEMICS).

1.2. Consumer participation and CanNET

Consumer participation is a core guiding principle for the CanNET Program and for Cancer Australia overall:

"Engaging and supporting the participation of people affected by cancer ('consumers') in our program development and priority-setting processes is pivotal to achieving Cancer Australia's aims." [3]

For the CanNET Program, consumer participation is one of three key elements to improve cancer care and outcomes – **active consumer involvement**, effective primary care involvement and multidisciplinary care:

"To ensure health care providers are focussed on addressing the needs of people affected by cancer, particularly those in rural areas." [4]

This project represents a key starting point with the involvement of consumers in this process both informing the key directions for CanNET Victoria and at the same time creating the beginnings of a consumer participation strategy.

1.3. Consumer participation – key drivers

Consumer participation is a concept and practice that initially emerged in the 1970s in the World Health Organisation principles for effective primary care and was later embedded as one of ten key principles in the declaration of Alma-Ata:

"The people have the right and duty to participate individually and collectively in the planning and implementation of their health care." [5]

Since that time, the need for consumer participation has been increasingly recognised in national and international policy and practice. Many examples of consumer participation at a range of levels have emerged over time. Whilst progress is clear, many challenges to effective participation are also recognised, not least of which is the lack of a tangible culture shift required to embed active participation of consumers as a core and routine part of health care delivery, service planning and quality improvement.

In the cancer field, Cancer Care Scotland has played a key leadership role in consumer participation following significant government commitment and investment in developing thorough, inclusive and effective participation approaches. Some key elements of the Scottish approach include:

- Understanding the experiences of people

affected by cancer as the key to initiating meaningful involvement

- Use of methods to maximise engagement with people from all walks of life in their local communities
- A focus on the person with cancer and the totality of experience as opposed to a disease-focussed model
- The development of a dynamic consumer participation model focused on partnerships, patient and public outcomes and underpinned by research, service improvement, engagement and experience.[6]

In Victoria, legislative and other policy mandates require health services to embed consumer participation into their organisational structure and processes. Key quality bodies such as the Victorian Quality Council, the Australian Council on Healthcare Standards and the Quality Improvement Council have included requirements for consumer participation in key quality measures and standards linked to accreditation and government reporting and accountability mechanisms.

Key policy direction for consumer participation in Victoria is provided in:
- Doing it with us not for us[7]
- Participation indicators[8]
- A guide to enhancing consumer and carer participation in Victoria's Integrated Cancer Services.[9]

1.4. Levels and types of consumer participation

Four levels of consumer participation are recognised:
- Individual
- Program / department
- Organisational / health service
- Statewide.

Five types of participation are consistently described in these policy documents as outlined in Table 1.

Table 1. Types of consumer participation[7]

Participation Type	Description	Examples
Information	To support participation, convey facts and educate so that people affected by cancer can take an active role in decision making and in their own care as is their preference.	• Information resources development and provision – what to expect, how best to manage the effects of the cancer and its treatment • Use of decision aids • Audiotaping / written summaries of key consultations • Question prompt sheets • Information about who to contact if needed • Supported education and training to build the confidence, skills and knowledge required for effective problem solving and self-management • Community education / public information campaigns • Actively assessing preference for information provision and level of involvement in decision making
Consultation	Seek the views of people affected by cancer to inform service planning, service improvement, research, policy or treatment decision making.	• Public meetings / forums • Focus groups • Interviews • Surveys • Consumer feedback mechanisms • Consumer reference groups • Discussion papers • Consumer and carer / family meetings

Partnership	Processes within which joint decision making is undertaken by consumers, carers, community members, health service representatives and/or government to determine policy direction, research priorities, service planning and delivery.	• Representation of consumers on boards, advisory groups / committees, working parties
		• Community Advisory Committees
		• Volunteer roles
		• Consumer advocates / consultant roles
		• Involvement of consumers in:
		  o Research
		  o Evaluation
		  o Quality improvement processes
		  o Health professional recruitment, education and training
		• Support group facilitation (may be in partnership or wholly consumer-driven)
		• Shared decision making
		• Production of information materials

Delegation	Consumers, carers and community members have decision making roles and responsibilities within specific areas of focus to ensure policy decisions are independent and linked to community needs and accountability.	• Ethics committees • Public enquiries • Health service boards
Control	Decision making power is given directly to the people whether that be the electorate, a consumer of health care or carer.	• Referenda • Board of management with representatives elected from within the community

1.5. The impacts of consumer participation

The evidence base for understanding the impact of consumer participation is limited by a lack of a focus on evaluating the outcomes of participation activities and disseminating experiences and outcomes in the field. There is, however a slowly growing body of evidence of impact including the following findings:

- Increased relevance of research
- Health care service changes
- Improved symptom management, psychosocial wellbeing and partnership working
- Personal empowerment
- Increased knowledge
- Increased mutual respect and comfort in working together – health professionals and consumers
- Decreased anxiety, depression and increased confidence
- Participation in care, self management and education has been reported to improve health status, reduce hospitalisations, presentations to Emergency Departments and unscheduled visits to Doctors.[9, 10]

1.6. Barriers to effective consumer participation

Commonly cited barriers to effective consumer participation include:

- A lack of commitment and understanding by senior management and / or clinical staff
- Failed past experiences with consumer participation
- Dominance of a medical model over a social model of health
- Involvement of consumers as an afterthought rather than a key element embedded into planning, systems and processes
- Mutual suspicion:
    o clinical staff / management concerns and resultant defensiveness about consumer participation as a punitive 'blame game'
    o consumer concerns about speaking up and its potential influence on their ongoing care
- Consumer participation driven and developed according to the needs of services rather than the needs of consumers (often resulting in tokenism)
- Lack of structures and resources to recruit, support and sustain participation – often consumer participation is not specifically funded, nor are there the human resources allocated to provide adequate support to ensure its successful implementation
- The limited timeframes, focus and capacity that can exist within project-based initiatives can introduce barriers to effective engagement and sustainability as well as the capacity to address issues of interest to consumers that would come from longer term engagement
- Lack of training for health professionals and consumers – often training focuses on training consumers in how to articulate their concerns rather than on training health professionals in how to listen and respond
- Cost and logistics of participation (particularly in regional areas).[9, 11, 13]

"The cultural shift… necessary to attaining effective involvement has a long way to go. It appears that significant challenges remain in convincing many clinical staff and managers, often those in influential

positions, that involving people affected by cancer is beneficial and worth their while in terms of investing time and resources, given the multiple and competing demands on the clinical workforce." [12]

1.7. Enablers of effective consumer participation

"The actual experience of engaging with the agenda of involvement can dissipate some of the concerns that health professionals may have." [10]

Reflecting these barriers, Table 2 presents the DHS principles for effective consumer participation.[7]

Table 2. Principles to guide effective consumer participation

Principle	Description
Trust	Mutual agreement on processes and productive working relationships
Respect	Mutual respect amongst participants as equal and valued contributors to a process
Openness	All participants are open to hearing and considering the views of consumers, carers and the community and accept the need for change
Equal opportunity	Involve those affected by decisions, inform them of the process and ensure access to information and the means required to participate
Advocacy and support	There is support for participation from the top and participation is adequately resourced
Responsiveness	The organisation is skilled in consumer participation and multiple strategies and resources are in place
Shared ownership and accountability	There is shared ownership of the participation process and outcomes by all involved and shared responsibility taken for monitoring and evaluating impact and outcomes. These responsibilities are clearly defined and agreed up front
Dissemination	Decisions made and mechanisms for participation are communicated to all involved in and affected by the decisions
Evaluation	Lessons are routinely identified and communicated widely

Effective consumer participation will ideally involve a long term commitment and overarching sustainable strategy that is well resourced and valued as a core part of the work of an organisation. It would address the range of levels of participation from enabling individual people affected by cancer and their carers and family members as partners in their own care to partnerships with consumers to enable system and service improvements. Key elements of an optimal approach drawn from the literature and key policies are described as:

- A shift in attitudes and roles from professional paternalism to a partnership approach

- Development of a range of mechanisms for participation established and shaped by the consumers themselves
- Optimising recruitment through personal invitations to participants and open membership – going beyond existing networks eg. local radio, newspapers, community venues
- Clarity of the scope and nature of involvement and expectations
- Having funding to cover and a clear policy and processes in place for the reimbursement of expenses incurred by participants as a consequence of their involvement (including consideration of sitting fees, travel, parking, childcare costs)
- Providing training, mentoring and support to health professionals in working with consumers and for consumers who become involved
- Patience and continual encouragement
- Providing information to potential consumers about the participation processes and contextual information about the service / project and their role
- Ensuring sufficient dedicated human resources are allocated to supporting and facilitating the development, maintenance and coordination of consumer participation mechanisms and the provision of support to individual consumers as required
- Having multiple mechanisms for participation to cater for the diversity in preferences and availability of consumers and carers – a flexible and responsive approach to facilitate optimal involvement
- Clearly acknowledging the involvement of consumers
- Reporting on outcomes of activities to all involved and the community as relevant
- Embedding mechanisms for evaluation and reporting on the consumer participation approaches and impacts. [9, 11, 12, 13, 14]

The concepts described in this section, coupled with the findings of the consultations undertaken in this project have shaped the proposed consumer participation strategy for CanNET Victoria outlined in section 6 of this report.

2. The CanNET Victoria Consumer Participation Project

In late 2007, CanNET Victoria commissioned this project to consult with people affected by cancer to shape and inform CanNET Victoria initiatives and the development of an ongoing strategy for consumer participation for CanNET Victoria.

2.1. Project aims

The Project aims were to:

- Consult widely with consumers to guide CanNET planning activities and to ensure that all core initiatives are guided by consumer perspectives and expressed needs including the development of a:
    o Services directory
    o Professional development program
    o Strategy for enhancing multidisciplinary care
- Develop a consumer participation strategy for CanNET Victoria that will enable ongoing, effective and meaningful participation by consumers and that includes:
    o The identification of consumers and invitation to participate in CanNET planning, implementation and evaluation processes
    o Support and training provisions required to optimise consumer participation and to ensure their safe and valued participation
    o Strategies for ongoing and periodic consumer participation.

2.2. Key project definitions

For the purpose of this project, the following definitions were applied:

- A **'consumer'** was defined as a person from the Hume RICS or NEMICS region who has a personal experience of cancer as a patient, carer, family member or friend.

- An effective **'consumer participation'** strategy was recognised as requiring a range of mechanisms for consumer involvement in their own care, in service planning and service improvement activities. Consumers would participate in one or more activity at any of those levels guided by their preference and capacity.

2.3. Recruiting participants

Twenty-one towns / suburbs across the Hume and North Eastern Metropolitan regions of Victoria were chosen where consultations (individual interviews and group meetings) were planned and promoted for the period 25th February to 19th March. Advertisements, flyers and information sheets were produced to support information provision and recruitment of potential participants.

A range of activities were undertaken to promote consultation opportunities in the relevant areas including advertising in local newspapers and through mail, email and phone contact with local health service, community and consumer networks and organisations including:
- Public and private hospitals (CEOs, DONs, key cancer services personnel, care coordinators, cancer nurses group, radiation oncology)
- District nursing, community health and palliative care services
- Divisions of General Practice
- Support Groups
- Individual consumer contacts known to NEMICS and Hume RICS
- Community agencies and groups (Probus, Country Women's Association, Lion's Clubs, RSLs, libraries, Rotary, Senior Citizens groups).

Support and active promotion of the meetings was also provided by NEMICS personnel and other interested parties in the field. In addition, further promotions were initiated in some towns, including publicising the meetings on local radio, publishing editorials in local newspapers and advertisements on local community websites.

Specific activities were undertaken to engage with local Aboriginal and Iraqi communities in the Shepparton area to enhance diversity in participation. Whilst initial responses were positive, specific consultation activities were not able to be undertaken within the timeframe of the project. Continued work to engage and incorporate the needs of diverse cultural groups would need to be undertaken beyond this project phase.

2.4. Consultation method

Four key elements made up the approach to the consultation and data collection process for this project:
- Group meetings
- Individual interviews
- Collection of demographic information
- Creating a register of interested consumer participants

2.4.1. Group Meetings

The group meetings sought to capture the nature of participants' experience with cancer, challenges faced and areas for improvement with a focus on:
- CanNET Victoria
- Consumer participation opportunities and strategy development
- Identifying key opportunities or priorities for service development from the consumers' perspectives
- Informing the focus of key CanNET initiatives and priority areas including:
  o Professional development
  o Service directory development
  o Enhancing multidisciplinary care

2.4.2. Individual interviews

The individual interviews were designed as a key mechanism to develop rich stories and accounts of personal experiences of cancer for consumers across the Hume region. They were designed to provide material to develop a series of de-identified case studies to add

a depth of understanding of the consumer experience beyond what can be captured in a survey or described in the text of a report.

2.4.3. Demographic survey

A brief survey was administered that collected information about the demographics of each participant and the people in their life affected by cancer (if they had not experienced cancer themselves). Topics covered included:

- Gender, age, area of residence, country of birth, language spoken at home
- Nature of experience with cancer – carer, personal experience, tumour type, current status
- Information about treatment – nature of treatment and places where treatment was received.

2.4.4. Register of consumer participants

Participants were asked to consider whether they would like to consent to register their contact details on a consumer participation register to be made available to CanNET Victoria, NEMICS and Hume RICS for the purposes of:

- informing participants of the findings of the current project
- inviting participation in future service improvement initiatives

An opportunity to register was also provided to other people who made an enquiry in the latter phases of the project and who were unable to participate or who wanted to distribute information through their networks.

2.5. Description of participants

A total of 128 individuals participated in a group meeting (n=102) or individual interview (n=28).[1] Of the individual interviews, 11 were conducted in person and 17 via telephone. Table 3 illustrates the number of participants by town.[2]

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[1] Whilst total participants in all activities was 130, two individuals participated in two activities – one attended two group meetings and one participated in both an individual interview and a group meeting thus the total number of individual participants was 128.
[2] For the face-to-face interviews this is the town in which these interviews were held; for the telephone interviews this is the nearest town to the participant's place of residence.

Table 3: Participants in a group meeting or interview by town

Town	Attended a group meeting	Completed an individual interview	Total
Albury / Wodonga	3	4	7
Alexandra	4	1	5
Beechworth	0	1	1
Benalla	16	6	22
Cobram	2	1	3
Corryong	17	1	18
Craigieburn*	1	1	2
Euroa	2	0	2
Heidelberg*	0	2	2
Kilmore	1	0	1
Mansfield	5	1	6
Myrtleford	6	0	6
Numurkah	10	0	10
Ringwood*	4	0	4
Seymour	1	1	2
Shepparton	1	3	4
Tallangatta	2	0	2
Wangaratta	11	5	16
Yarrawonga	12	1	13
Yea	4	0	4
Total	**102**	**28**	**130**[1]

- Most participants were from the Hume region of Victoria
- Three meeting locations and individual interviews were promoted in areas close to NEMICS services(*), although only 8 people participated in total
- The number of participants in group meetings ranged from 1 to 17 (mean = 5)

Table 4 illustrates the experience of cancer for the 128 unique participants.

Table 4: Experience of cancer amongst consultation participants

Nature of experience of cancer	Number	%
Personal experience of cancer	67	52.3
Personal experience of cancer and also a carer for a person with cancer	12	9.4
Carer of a person with cancer	44	34.4
Indirect experience	5	3.9
Total	**128**	**100.0**

- 62% of participants had personally experienced cancer themselves
- Of the 79 people with a personal experience of cancer, 12 had also, or are currently involved in caring for a family member with cancer
- Of the 56 carers, 12 participated with the person they are caring for
- Those classified as having an 'indirect personal experience' of cancer included:
  - Three health professionals who work directly with people with cancer in community and district nursing roles

o A person with a professional interest in issues relating to transport access through the 'Transport Connections Project'
o A cancer support group coordinator.

Of the 123 participants with a direct experience of cancer (personal and/or carer experience), 117 (95%) completed the demographic survey. Box 1 provides a snapshot of their key demographics.

BOX 1: PARTICIPANT DEMOGRAPHICS

Gender
93 women and 24 men

Age range
From 9 to over 80 years

Country of birth
109 people were born in
Australia, 6 in England, 2 in
New Zealand, 1 in India and 1
in Holland

Language spoken at home
One participant did not speak English at home

Aboriginal or Torres Strait Islander origin
One participant had Aboriginal or Torres Strait Islander origins

Carer relationship to person with cancer
Of carers who participated, they had cared for a:
• Spouse – 47%
• Parent – 23%
• Sibling – 13%
• Son or daughter – 11%
• Other family member – 6% eg. niece, grandparent

Box 2 provides a summary of the cancer experiences represented by participants i.e. their personal experience (if relevant) and/or the experience of the person with cancer that they spoke of (if a carer). In total, 119 experiences of cancer were captured in the demographic survey.

BOX 2: CANCER PROFILE

Tumour type
- 130 primary tumours were recorded
- 11 people had experienced two primary cancers
- 25 tumour types were represented

Year of diagnosis
- 54% of diagnoses were in the past 5 years
- 39% of initial diagnoses were prior to the year 2000, although 11% of those people were currently receiving treatment for their cancer at the time of consultation

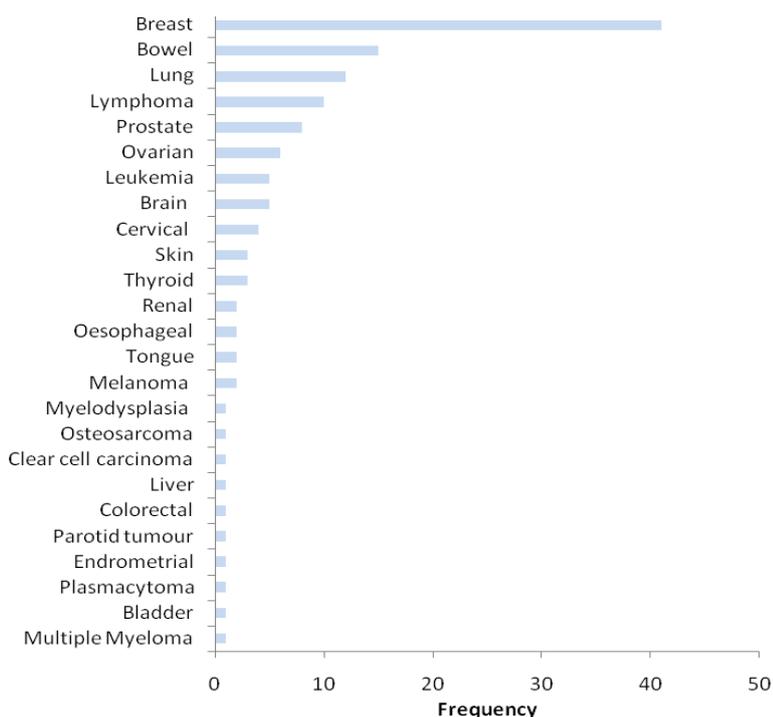Chart — Frequency of tumour types (horizontal bar chart, x-axis "Frequency" 0 to 50):

Tumour type	Frequency (approx.)
Breast	41
Bowel	15
Lung	12
Lymphoma	10
Prostate	8
Ovarian	6
Leukemia	5
Brain	5
Cervical	4
Skin	3
Thyroid	3
Renal	2
Oesophageal	2
Tongue	2
Melanoma	2
Myelodysplasia	1
Osteosarcoma	1
Clear cell carcinoma	1
Liver	1
Colorectal	1
Parotid tumour	1
Endrometrial	1
Plasmacytoma	1
Bladder	1
Multiple Myeloma	1

Current status
Of people with cancer represented in these consultations:
- 46% had completed active treatment
- 27% were deceased (represented by a carer)
- 26% were still undergoing active treatment

Treatment
A range of treatment combinations were reported:
- 28% had a single treatment type (18% surgery only, 5% chemotherapy only, 5% radiotherapy only)
- 77% had surgery (alone or in combination with other adjuvant treatment)
- 58% had chemotherapy (alone or in combination with other adjuvant treatment)
- 55% had radiotherapy (alone or in combination with other adjuvant treatment)

Access to additional services
76% reported accessing one or more other service. Services accessed were:
- District nursing – 34%
- Counselling – 32%
- Physiotherapy – 31%
- Palliative care – 26%
- Dietetics – 22%
- Social work – 20%
- Other – less than 6% (home help, occupational therapy, speech pathology, dental, eye specialist, gynaecology, podiatry, lymphoedema practitioner, education services)

While the participants' cancer experiences related to over 25 different types of cancers, this spread does not reflect the overall incidence of cancer. In particular given the relatively small number of men interviewed, prostate cancer experiences are relatively poorly represented.

The place of treatment was of particular interest given the focus of CanNET Victoria on quality care as close to home as possible and also strengthening rural cancer care.

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Information about place of treatment was available for 110 people affected by cancer, 6 from the north eastern metropolitan region and 104 from Hume. Box 3 summarises the patterns of treatment and distances travelled for treatment for people living in the Hume region.[3]

BOX 3: WHERE PEOPLE TRAVELLED FOR TREATMENT – PEOPLE WITH CANCER FROM THE HUME REGION

Local treatment (within 50 km of home)
47% of people received local treatment for their cancer:
- 10% for all of their treatment
- 37% for some of their treatment

Travelling to Melbourne
60% of people travelled to Melbourne for treatment:
- 15% for all aspects of their treatment
- 45% for some of their treatment

Metropolitan / rural split
Respondents were asked to estimate the proportion of their treatment that was conducted in the rural region or in Melbourne.

Percentage split	Number	%
0-25% metropolitan / 76-100% rural	62	54
26-50% metropolitan / 51-75% rural	15	13
51-75% metropolitan / 26-50% rural	9	8
76-100% metropolitan / 0-25% rural	28	25

Treatment within the Hume region
For treatment provided at services in the Hume region:
- 42% was within 50 km of the person's area of residence
- 22% was between 50 and 100km of the person's area of residence
- 36% was more than 100km from the person's area of residence
So, inter-regional travel in many instances still involved significant distances.

Table 5 illustrates the places of treatment quoted by respondents by town (as determined by the series of towns included in these consultations).[4]

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[3] As defined by Hume RICS.
[4] Note that in some instances, people lived in other towns in the surrounding areas so actual distances travelled for treatment may exceed those in Table 5.

Table 5. Places of treatment cited with approximate distances traveled

Town	Treatment locations	Approximate Distance (km)
Albury/Wodonga	Melbourne	256
	Canberra	345
	Albury/Wodonga	Local
Alexandra	Melbourne	96
Beechworth	Melbourne	223
	Wodonga	39
Benalla	Melbourne	167
	Albury/Wodonga	113
	Wangaratta	41
	Shepparton	61
	Benalla	Local
Cobram	Albury/Wodonga	129
	Melbourne	220
	Shepparton	57
	Wangaratta	92
Corryong	Melbourne	318
	Wangaratta	187
	Albury/Wodonga	122
	Corryong	Local
Euroa	Melbourne	130
	Albury/Wodonga	158
Kilmore	Melbourne	58
Mansfield	Melbourne	131
	Albury/Wodonga	176
	Wangaratta	103
	Mansfield	Local
Myrtleford	Melbourne	209
	Albury/Wodonga	69
	Wagga Wagga	101
	Wangaratta	47
Numurkah	Shepparton	33
	Albury/Wodonga	153
	Melbourne	196
	Numurkah	Local
	Bendigo	154
Seymour	Melbourne	140
Shepparton	Melbourne	164
	Shepparton	Local
	Bendigo	122
Tallangatta	Melbourne	265
Wangaratta	Albury/Wodonga	71
	Melbourne	203
	Wangaratta	Local
Yarrawonga	Albury/Wodonga	93
	Melbourne	221
	Wangaratta	56
	Yarrawonga	Local
Yea	Melbourne	79
	Shepparton	121

Distances travelled for treatment varied from local treatment in their home town to in excess of 300 kilometres for some to travel for Melbourne for treatment. Other locations of treatment outside the Hume region were also cited including Bendigo and Canberra.

3. Experiences of cancer care

Participants were asked a range of questions about their experiences of cancer care. More specifically they were asked to identify:

- Challenges they faced
- Aspects of care they valued
- Possible improvements for the future – making it better.

Each of these experiences is discussed in more detail below. The tables in this section have a frequency column. The frequency was calculated by adding the total number of group meetings and individual interviews in which that issue was raised. It does not represent the number of people who experienced this challenge (this would be a much greater number as each challenge was usually shared by more than one participant in each group meeting). The frequency column has been used to order and prioritise the issues raised.

3.1. Challenges faced

Participants were asked to identify and describe the challenges they experienced during their cancer care. Some of these challenges were specific to the experience of cancer as a person living in a rural area, whilst others were issues that were more general and unrelated to area of residence.

Summary of challenges faced

Travel: time, distance, cost, time away from family, logistics, burden on others and travelling when feeling unwell.

The financial impact of cancer: contributes to additional stress, cost of treatment, medication, scans, needing to pay upfront, impacts of the loss of income, claiming expenses is cumbersome and eligibility limited.

Access to information: limited practical information, knowing what to expect, what questions to ask, specific information about your cancer type.

Access to support: people with cancer needing someone to talk to, support for family and carers.

Communication and continuity of care: needing to be your own advocate, poor information flow back to GPs, mixed messages, contradicting information, communication skills of providers, finding things out by accident.

Waiting times/delays: waiting during times of uncertainty, waiting for appointments or treatment.

Facilities and staffing: crowded facilities, lack of privacy, stretched staff.

The stigma of cancer and existential challenges: how people respond to you, the association between cancer and dying and facing your mortality

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These challenges are further described below.

3.1.1. Travel

Travel was the most frequently reported challenge with the range of issues relating to travel listed in Table 6 in order of frequency.

Table 6: Challenges cited related to travel

Challenge described	Frequency
Travel	**27**
Time / distance	14
Logistics and burden to others	11
Accommodation – access and cost	11
Cost	9
Travelling when feeling unwell	8
Unable to claim VIPTAS	6
Emotional and physical impact - exhaustion, stress	6
Isolation/ distance from family	4
Lack of consideration of distance by providers	4
Travelling long distances for minor procedures or 10 minute consultations	4
Access to travel if you don't have your own means	3
Wanting to retain independence/ dignity	2
Not receiving information about the travel allowance	2
Finding parking	2
Having to relocate to Melbourne	1

People living in rural areas found the actual distance and time it takes to get to services in Melbourne to be the most challenging aspect relating to travel itself.

"The tyranny of the distance really does make it hard for us."

"It is dramatic for someone in rural or regional areas."

In addition, the logistics of travel and the burden this places on others was seen to be another challenge relating to travel that generated a significant level of stress and distress. This was reported by people from rural and metropolitan areas who commented on the burden on others, who had to drive them to and from treatment.

"Mentally that caused me more stress - how I was going to get around."

"My husband is legally blind and so he can't drive. We had to rely on the Red Cross and friends to transport us to the city. Sometime my husband couldn't come with me and that was really hard. Once I asked the driver to come up with me to the service as I didn't want to go alone. He did and that made a real difference to me."

Where people were travelling to Melbourne or to distant treatment centres from home in their region, this often also resulted in needing to stay there for a period of time, depending on their situation. Therefore they needed to find suitable accommodation, and in doing so, had to consider not only the cost associated with this, but the location in relation to their treatment site. In addition to this, costs associated with the actual travel itself, including petrol, wear and tear on the car or the cost of public transport were also a significant issue for participants in rural areas.

"It is devastating financially."

"I pretty much lived in Melbourne [over three hours from home] for a year during treatment. My wife and children [three children aged from 2 to 9 years at the time] started out coming to visit me on the weekends but it became too much for them. I would come home on weekends when I could…It was difficult for my family, my children especially - they always wanted to know when Dad was coming home."

Another challenge reported by people living in rural areas who had to travel, was facing these long distances when feeling unwell due to the treatment they were receiving. Often people were not driving and had to deal with nausea on public transport, which was an additional challenge in itself.

"She used to sit there on the bus with a bucket and towels in case she was sick. The driver used to look after us and told us to sit up the front of the bus."

A lack of consideration of the distance needed to be travelled by service providers was also raised with many instances where early appointments were set or multiple appointments were spaced out over the course of a whole day leading to protracted waiting times. If relying on community transport services, travel would involve a whole very long day away from home and /or work regardless of the time needed for the individual appointment, test or treatment.

"I have to get up at 5am on the days we go there."

A key issue raised was also the lack of awareness and consideration for the elements of care such as testing that could be provided closer to home. The avoidance of even one long trip was seen as a significant relief for participants.

"We would have to travel to the Royal Children's Hospital for our blood tests to see whether [name] could start chemo. Sometimes, she couldn't and we'd have to come home again and wait for another time."

"I am having my first CT scan in Kilmore [after ten years of treatment for cancer]. The only reason I found out that there was one here was that I was in hospital with pneumonia early this year and I overheard someone talking about a CT booking. I asked the question and found out that I could have my scan here. That will save me one trip to Melbourne which is significant for me, but if I hadn't have overheard that conversation I'd never have known."

"Maybe we should have packed up and moved to Melbourne. We are trying to work out what to do now."

3.1.2. The financial impact of cancer

The next most commonly reported challenge was the **financial pressure** associated with a cancer diagnosis and treatment (Table 7). These pressures often overlapped and were associated with travel, however there were multiple additional issues that were also raised. People described the repercussions of a cancer diagnosis as leaving them *"financially crippled"*.

Table 7: Challenges cited relating to financial pressures

Challenge described	Frequency
Financial pressure	**26**
Need to pay upfront then seek rebate (still out of pocket)	9
Loss of income (personal and carer), taking leave without pay	8
Cost of medication / chemotherapy	7
Claiming expenses: cumbersome, fitting criteria, knowing process, burden	7
Costs of treatment (private / out of pocket)	6
Cost of tests/scans	5
Additional stress on top of what you are going through	5
Poor information about cost of treatment	4
Impact on small business owners who experience cancer	2
Cost considerations influenced treatment choices	2
Cost of parking	2
Inconsistent practice re: billing	1
Cost of prostheses / wigs	1

Participants frequently reported the costs associated with medication, in particular, chemotherapy, scans, tests, radiotherapy and other aspects of treatment as creating a substantial financial burden and cause of stress.

"They assume you have got the money to pay for the treatment."

Having to pay up front and then claiming available rebates afterwards was the aspect most commonly raised in relation to financial pressure. Not only did this mean that people had to have the lump sum of money up front, often there was also a significant difference or gap in what they paid and what they were able to claim back. This also linked with inconsistencies in systems for billing and payment between services or for different people at the same service.

"I saw people almost fall apart looking at the bills and the money they had to pay."

"Services would say payment on the day is appreciated. This is okay if patients can afford upfront costs."

"They don't want to know you until you get your cheque book out."

Financial pressure was commonly experienced due to a loss of income for either the person with cancer themselves or their carer. This loss of income was often temporary, while people were undergoing treatment. People commonly reported having to take leave without pay, or in some cases, people were forced to resign from their jobs. Participants talked about the fear of losing their job as a result of taking large amounts of leave, whilst others had to actually buy leave, so they could then take the time off. For business owners, additional challenges presented themselves in terms of maintaining their business and income during periods of illness and treatment.

"I didn't want to lose my job."

"We have actually had to buy leave so we can take extra leave when we need to."

"We had to manage on one wage and that was a struggle."

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"We had to relocate completely to Melbourne for three months [had twin babies at the time] which involved having to sell our restaurant. We lost a lot of money."

Whilst a range of mechanisms were quoted whereby assistance with the financial aspects of care could be provided, in most instances, these were not routinely conveyed to people affected by cancer. In addition, the actual process of claiming expenses or accessing available support payments was described as *"cumbersome"* and something that is difficult when you are feeling unwell. Issues were also raised about *"fitting the criteria"* in order to claim back some expenses and the challenges arising when you don't *"fit in the box"*. Many instances were cited where substantial distances were travelled that fell ten or 15 kilometres outside the 100 kilometre eligibility criteria for a one way trip to allow someone to claim part of their travel expenses through the Victorian Isolated Patient Transport Assistance Scheme (VIPTAS).

"That is something they need to be made aware of; when you have sick kids you just don't have time to fill in paperwork."

"Tears of frustration, anger and grief were shed in the Centrelink office"

Financial pressures were reported to result in additional stress for people with cancer, carers and families.

3.1.3. Access to information

"I want to be informed and have information at my fingertips."

The third most commonly cited challenge was a **lack of sufficient information** (Table 8). People described that information relating to a range of issues *"was not easily accessible"* and that they wanted to be informed. Issues related to the capacity to take information in were also raised and the need to multiple forms of information at different points in the pathway.

"You are in an emotional scramble and cannot think clearly."

Table 8: Challenges cited relating to a lack of information

Challenges described	Frequency
Lack of or insufficient information	**18**
Practical information – assistance, support	17
Specific to cancer type or circumstances	8
What to expect	8
What questions to ask	5
Screening – what to look for	1
What's normal	1
How to talk to kids about cancer	1
Options available	1

It was most commonly reported that there was a lack of practical information for both people with cancer and carers including information relating to support services available and the range of assistance that people could receive. As a result, they had to seek this information themselves and often became aware of services and assistance via word of

mouth or by accident. Key issues were not knowing what you didn't know, not knowing what you might need and thus not knowing what questions to ask to gain information or support to help them move through their treatment and recovery.

"I had to find out if there was transport, but it's only because of my initiative that I found this out."

"The medical fraternity doesn't make known the different services that are available to patients."

"I was told my hair was going to fall out, but where do I get a wig from?"

"There are lots of services available but how do you know about them if no-one tells you."

People with cancer, in particular, reported that there was insufficient information provided to them about the 'unknown' and felt that they were *"in the dark"*. They frequently commented on not receiving information about what to expect at various stages throughout their cancer journey, or what questions they should be asking clinicians. Often being in a state of shock, following a cancer diagnosis, this is the sort of guidance or information they would have liked to have received and therefore this was seen to be another challenge. Furthermore people wanted to know if what they were going through was *'normal'*.

"The scariest thing is not knowing what is ahead."

"It troubles me when people don't know what to ask."

"I couldn't work out if what I was feeling was normal, whatever normal is."

Participants also described the need for information that was specific to their cancer type or their specific circumstances. This was often identified by people who had less common cancers or who didn't fit a common profile for that cancer eg. a young sufferer of a cancer type commonly experienced in the elderly.

"Because I didn't have breast cancer, lung cancer or prostate cancer, they couldn't help me."

"No one bothered to tell me there were different types of breast cancer."

Other challenges people identified were a lack of information relating to:
- Screening and what to look for
- How to talk to children about cancer- *"A lot of parents don't know how to talk to their kids about their cancer"*
- Options available – in the first instance, that options did exist and what they were.

3.1.4. Access to support

Another challenge that was recognised was the lack of **support and support services** for people with cancer, carers and families (Table 9).

Table 9: Challenges cited relating to access to support and support services

Challenges described	Frequency
Not having someone to talk to	8
Support for family members	5
Counselling support for the person with cancer	4
Who to ask for help from	3
Feeling helpless / role challenges	3
Support for carers	2
Bereavement support	1

People with cancer in particular, commonly said that they needed someone to talk besides friends or family, and didn't know where to turn to. This was often related to not wanting to further cause distress to carers or family members. Watching partners and family members suffer was cited as a very difficult aspect of the experience for a person with cancer.

"I had no one to talk to at the time as I didn't have a partner."

"There is no one else I can tell this to. My mum, I try to protect - my husband and I try to forget it, we don't talk about it, and I don't want my son to come and be exposed to this (treatment and environment)."

"The biggest issue for me was not being able to talk with anyone about what I was experiencing at the time."

Access to other emotional or practical supports were also raised as key issues.

"There was no access to home help - you have to do it yourself or rely on friends."

"I was looking for support because I didn't know what I was going to be going through, but there was nothing."

In addition to this, participants reported that support for family members and / or carers was rarely offered and people were unsure of what was available and where. As with other aspects of care, this was something they had to find themselves.

"No one suggested that I might need some help."

"Carers get the raw deal – they are always asked how you (the patient) are going, not how they are coping. Everything focuses on the patient not the carer."

"This often isn't offered but rather you have to source it yourself."

When a person has died of cancer, bereavement support / counselling in the lead up and after death for the person themselves, their carer and family members was raised as a key issue. There was a sense that once out of the treatment sector, that all supports that were available drop off and people were alone to deal with their grief. Examples were provided where substantial unresolved issues remain with regrets, grief and ongoing impacts on individuals and families, in one instance, many years down the track.

3.1.5. Communication and continuity of care

A range of challenges were also raised relating to **communication** and **continuity of care** (Table 10).

Table 10: Challenges cited relating to communication and continuity of care

Challenges described	Frequency
Need to be your own advocate - *'detective'*	13
Mixed confusing messages	9
Access to GPs and variability in quality	8
Communication skills of care providers	8
Finding out about services or information by accident	6
Information flow back to GPs	5
Having to repeat your story	3
Having medical support on hand when things go wrong	1

The most frequently identified issue was that there was a need to be your own advocate or *'detective'* in order to get questions answered or to find the information you required and this was described as another *'battle'* you had fight.

> *"I rang everybody to find out what I needed to find out."*

> *"I had to do battle for him on some occasions."*

It was also challenging for people with cancer and carers when they were faced with mixed messages or contradictory information. There was a sense of not knowing who to believe or who was correct and during times of hardship, this was extremely difficult.

> *"Being given incorrect information made me lie to my GP."*

> *"I lost all faith in the medical system…didn't know who to believe."*

Participants also identified that there was poor information flow back to their GP. This often resulted in people with cnacer or carers having to chase up information that should have been forwarded to their local doctor.

> *"Sometimes my local doctor is out of the loop."*

Furthermore access to GPs and variability in the quality of care provided by GPs was another challenge, particularly for people in rural areas.

> *"The country GPs are not familiar with all the cancers."*

> *"I couldn't go to the local GP because they didn't know what to look for."*

> *"There are not enough GPs. You have to be having a heart attack to be seen straight away."*

3.1.6.　Waiting times / delays

"Once exiled from the Kingdom of the well to the land of the sick your time is meaningless."

Another significant challenge that participants raised was **waiting** either during times of uncertainty or simply for appointments, treatment or tests. This was particularly challenging in the lead up to a diagnosis where participants said they had to undergo a range of procedures and waiting to hear these results was *'torture'*.

"The time from the initial mammogram to the diagnosis was the worst time of my life - just that waiting."

"Waiting is an agony all of its own, it is a terrible time."

Delays in diagnosis were also a very significant issue for a small number of participants relating to both the time taken to reach a definitive diagnosis often involving months of waiting and tests and in one instance, two years. In this instance, the person with cancer experienced symptoms and sought help but was continually told that nothing was wrong and she had nothing to worry about. By the time a diagnosis was made, the cancer was in advanced stage.

"I know my body and I knew something was wrong…In the end it was an absolute relief to be told I had cancer…'Doctors – take women seriously if they say they have a problem with their body'."

3.1.7.　Facilities and staffing

Actual **facilities** within treatment centres and **stretched staffing** were also identified by participants as challenges. Crowded facilities, particularly when people were having chemotherapy, often resulted in limited privacy and was noted to exacerbate distress. This also flowed on to people not asking questions or seeking assistance due to how busy staff were in these situations.

"In the waiting room, if I feel like I'm going to vomit, I know if I go out I won't get a seat when I return…In the chemo room, if someone vomits it has a cascade effect…there is not enough room to even recline the chairs so I can't even lie back and shut my eyes to try and shut out what is happening in the room."

"You were so rushed, you didn't even get a proper explanation."

"The nurses are just flat out. Sometimes it would be nice when having the chemo to ask questions I have."

Access to local palliative care beds, to medical specialists in the local area or support when things go wrong at home were a significant issue for some individuals.

3.1.8.　The stigma of cancer and existential challenges

Another challenge which was raised predominantly by people with cancer was the stigma surrounding cancer. They identified that following their cancer diagnosis, people didn't know how to react or treat them. In addition, the association with cancer and dying was identified as a challenge.

"People treat you like you have something contagious."

"People do look at you differently when you have a diagnosis of breast cancer and people do treat you differently."

"My son was shocked when he found out I had cancer, because we had heard you die from cancer."

Closely linked to this was the reality of facing your mortality and living with uncertainty. Whilst people often identified that they were in remission, the fear that *'the cancer may come back'* was extremely challenging and difficult to deal with. Furthermore the actual struggles of living with cancer were also identified as being difficult.

"The biggest challenge was I thought that I was going to die."

"When I was diagnosed with secondary cancer, it was really difficult – you wonder if life is worth living after that – it has been hard, really hard."

"The biggest challenge is accepting that you are not immortal...and understanding the reality of your situation."

"Will the cancer come back?"

3.1.9.   Other challenges

Other challenges that were identified less frequently by participants included:
- Needing support after treatment was completed - *"I had fantastic support and then at the end, I felt a little on my own."*
- Difficulty re-accessing the system down the track - *"There is such a focus on the short term but not the challenges in the long term".*
- Differences in quality and levels of support between public and private services
- Social isolation - *"I felt isolated in my local area."*
- Chemotherapy itself - *"I hated the chemo - when I got to the last one, I drove all the way in crying and all the way home crying."*
- Receiving your choice of treatment - *"I had to speak to four different surgeons before I found one who would do the surgery I wanted."*
- A series of examples where existing personal challenges made a substantial impact on the cancer experience including social issues, family conflict, existing carer responsibilities for the person with cancer, children with cancer whose parents had divorced and remarried.
- The challenge of staying positive - *"You have to think positively and think that every day is a bonus."*

3.2. Valued aspects of care

A principle objective of the consultation process was to draw upon participants' experiences to identify key aspects of care that were valued so that these could be highlighted and reinforced in any strategies arising from this work.

Summary of valued aspects of care

Personal characteristics of individual care providers: listening, taking the time, the *'human touches'*, caring, approachable, remembered me, answered my questions, honesty.

Specific service providers: individual specialists, palliative care, district nursing, local GPs, social workers and breast care nurse.

Specific services: Look Good Feel Better Program, Cancer Council Victoria Helpline, Royal Children's Hospital Rural Outreach and Shared Care Program.

Valuable supports: for patients and carers such as family friends, workplace support, community and peer support.

Overwhelmingly, participants described the things they most valued as relating to elements of supportive care eg:
- caring demonstrated by individual service providers
- support received from people close to them and their community
- a range of specific services that were considered to be of great support to them.

In addition, communication, continuity of care, follow-up and care close to home where possible were highly valued.

3.2.1.   Personal characteristics of individual care providers

In responding to this question, many respondents made comments such as *"my Doctor was amazing"* and *"the nurses were angels"*. These comments were further explored through asking what specifically was it about those people and the care they provided that you valued (Table 11).

Table 11: Personal characteristics of care providers that were valued

Valued aspects of care	Frequency
"Human touches" – demonstrating caring	19
Approachable, took time, remembered me	15
Answered my questions / good explanation	12
Accessible – call anytime	10
Flexibility and responsiveness – listen to me	9
Follow up	8
Confidence in their competence	7
Honest / straightforward balanced with hope	7
Provided information to person with cancer / carer / family	4
Communication skills	3
Looked beyond my physical needs	3

'Human touches' and a sense of being cared about were highly valued with many examples provided of small gestures that demonstrated caring and consideration by the service and / or individual practitioners or other staff in treatment services.

"The human touch is very very important."

"The male nurse just came one night and sat there with me - it meant more than a thousand words."

"The care I have received has saved my sanity. My nurses are awesome. I call them my 'blue angels'...there is authenticity about their care".

*"The head of oncology sometimes even goes to patients' funerals, they care **that** much."*

Key characteristics cited as demonstrating caring were when clinicians were **approachable**, and they had time for them. In addition to this, **remembering them** by sight or by name made people feel valued.

"The staff know who you are, and you aren't just a number."

"They made you feel special, you were an individual"

"I valued being treated as a person and not just as a sickness. The nurses know and understand my situation."

Other characteristics valued included the ability to **answer questions** that not only people with cancer may ask, but also carers and other family members, in a language that they understood. **Clear explanations** about their diagnosis and progress, processes, procedures, treatments and other important aspects of care were highly valued. This required clinicians to have the skills to tailor their approach, depending on the individual.

"The staff talk you through what you are having. They say if you are having any problems, if you have any questions just ask, even if you think they are silly questions."

"He provided facts I could understand and a pathway for treatment".

People with cancer and carers both equally valued it when clinicians told them they were accessible or **available at anytime**. This was described as reassuring, knowing that in times of need, someone was there for them, regardless of what day or time it was.

"Sparing their own private time for patients is amazing."

"The local GPs gave you their home phone number and said to call any time."

Listening to the person with cancer and their carer was appreciated and identified on numerous occasions as a valued aspect of care. Allowing people to raise their concerns or fears, or simply having someone to listen to you, besides a family member or friend was seen to be invaluable. It was this **flexibility and responsiveness** to people's needs, which clinicians often displayed, that was highly regarded.

"There is always someone there to listen."

Participants often cited **follow up** in between treatments or after treatment had completed as an additional valued aspect of care that also provided reassurance. Sometimes this was in the form of a phone call from their local GP or a clinic nurse, *"just to see how they were going".*

Other valued characterstics were **honesty** and the ability to deliver **straightforward** information or news that was also **balanced with hope**.

"I valued their honesty and they don't try to gloss things over."

"Someone who is open and honest and tells you how it is."

"You don't want to put someone on a death wish...but it is about balance, and you do want to know."

3.2.2. Specific service providers and services

A range of specific services and service provider groups were cited as examples of valued aspects of care (Table 12).

Table 12: Valued services and service provider groups

Valued aspects of care	Frequency
Local care – GP, tests, port management	13
Palliative care	10
District nursing	8
Social workers	6
Cancer Council Victoria Helpline / Resources / Programs	5
Counselling services	5
Local specialist services	5
Breast care nurse	2
Royal Children's Hospital Rural Outreach Shared Care Program	1

Specific services and service providers mentioned related often to locally available care – both specialist and generalist services as applicable to the area. This was seen as a highly valued aspect of care during the cancer journey. In some instances, this involved the

provision of local care such as symptom management or port care between chemotherapy treatments, access to local tests and specific services and supports available in the local area. A further benefit of this local care was seen as the opportunity to touch base with people, identify any unmet needs and facilitate linkage back into health services as required.

- Local GPs:
  "He never assumed he knew everything or was in control but worked together with the specialist to provide the care she needed."

- Local treatment services - Being able to have some aspects of treatment closer to home eg. visiting oncology consultations or more local availability of chemotherapy services was highly valued when available

- Palliative care service provision and the people providing those services:
  "These were magic people who helped amazingly. We tend to think of palliative care as just end of life, good-bye but we need to have less of the 'undertaker' view. We have to let them into your heart – into the intimacy of living and that palliative care is about a 'passage of living'. But this is not easy to do as we are all independent and my husband struggled with his loss of independence."

- District nursing services:
  "The district nursing were invaluable. They would sometimes just call in for a cuppa and they even trained me so I could help my husband."

  "The people themselves are divine."

  "The district nurse was fantastic - she spent time talking to my wife and was able to deliver the pain relief she needed."

- Counselling services:
  "The grief and loss counsellors are fantastic."

3.2.3. Other valued supports

Participants also described a series of other supports outside health care services that were a key to their coping with their diagnosis and treatment (Table 13).

Table 13: Other valued supports for people with cancer and their carers

Valued aspects of care	Frequency
Family/friends	24
Peers - Tips and hints, sharing information	10
Workplace	7
Having a support person available at appointments	6
Community – rallying around	6
Faith/Church	2

Support provided by **friends and family** was highly valued. Having someone to turn to in times of need or knowing that people cared was very important. Often this was displayed by simple gestures such as a phone call to see how they were.

"There is the secret; sharing the experience with your partner."

"My family, and in particular my husband, have been fantastic."

"I valued the tenacity of my husband."

"You appreciate when people ring and ask you how you are feeling today. It shows they are thinking about you."

"Surrounded by amazing friends and family we took this journey together."

"Essentially we are a tight knit unit – we stick together and support each other."

"The greatest care came from my husband…he would say the sweetest of things. I felt my chest was so ugly but he said 'I don't know what you are worrying about, when I hold you, your heart is closer to mine.'"

Another valuable support, particularly for people with cancer, was the ability to **share their experiences and stories** with people in a similar situation. It was often in waiting rooms that people would share their tips and hints as everyone knew they had something in common.

"What I valued was sharing information about my husband with other patients."

"We [cancer support group members] don't talk about breast cancer all the time but we do talk about how our lives are going and help each other."

As identified in the previous section, cost and financial pressure was a significant challenge for numerous participants, where many people had to take time off work, take leave without pay and even resign as a result of a cancer diagnosis. Having a **supportive workplace** was therefore seen to be highly regarded.

"My boss has had cancer so he understands."

People in rural areas identified that **community support** was also greatly appreciated. Knowing that there were people close by who cared and were there to *"rally around you"* was important to many participants.

"It is a wonderful thing when a small town like this can support each other."

"There is now a very good support system [in our local town] - if you are diagnosed with cancer, there is a casserole on your doorstep."

In addition, faith communities and simply having someone with you at appointments were also identified as being valued aspects of care for some.

"I valued my faith and found strength in that."

Other valued aspects of care were:
- Continuity of GP care
- Services that bulk billed
- Being treated in a pleasant environment
- Proactive services who offered support
- The opportunity to be involved in research.

3.3. 'Making it better'

Participants described a range of improvements that they considered would make the experience of cancer care a better one.

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Summary of improvement ideas

Improving information provision: particularly around practical information such as services and support available.

Increasing local access to services: where possible to reduce the burden of travel.

Improving information flow and communication: within and between service providers and with people with cancer and their carers and families.

Regular training for health professionals

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3.3.1.   Improving information provision

Enhanced information provision was seen as an important improvement with Table 14 summarising the most commonly cited ideas for improving information including suggested topics for focus.

Table 14: Improvement ideas – improving information provision

Improvement ideas	Frequency
How information is provided / specific issues	
Early access to information	9
Guidance for information seeking	2
Specific topics	
Knowing what questions to ask	6
Knowing what to expect and when	6
Financial support / options	5
Travel assistance / allowances and how to access	3
Specific information about cancer type	3
Choices / options	3
Cost of treatment and modes of payment	1
Insurance entitlements and restrictions	1

As **information** was identified as a significant challenge, it was not surprising that improving information provision was identified as essential. Participants identified that improvements could be made by facilitating and providing early access to information

and providing people with cancer, their carers and families with guidance relating to seeking further information.

"You need to know a series of questions to ask and who to ask these questions"

"You need to empower people to ask questions so everyone gets the same care."

"Information needs to be supplied by doctors that tells you about claiming travel"

Other areas of focus raised were:
- Informing people with cancer and carers of other things they can do to help them cope
- Making people aware of how they can help a friend with cancer

3.3.2.   Improving access to services

Improving access to services, particularly in the local area, was another possible improvement that was identified and seen primarily as a mechanism for reducing the burden of travel and also to better support and educate people to better manage.

Participants highlighted access to the following services or programs at a local level when speaking of possible improvements:
- Cancer support groups
- Support programs such as Look Good Feel Better
- Medical care and / or support between treatment or after treatment has finished
- Improving and raising community education and awareness
- Counselling including emergency counselling time slots in times of extreme need
- Improved access to appropriate and suitable facilities for inpatient palliative care in the local area
- Early access to social work
- Business counselling for business owners affected by cancer.

Access to free treatment or treatment within the public system was also raised with at least the communication of choices available as an important improvement. An example given was the provision of clear information about private sector treatment, logistics and costs (if that is the 'locally' available option) and about alternatives in the public system including the associated implications such as additional travel and accommodation to support informed choice.

One participant suggested that where access to local services was not possible, introducing virtual consultations may improve people's experience of care. In addition to this, one participant suggested the introduction of a mobile oncology service for chemotherapy provision.

Any aspect of care that could be provided locally was seen as a bonus, reducing travel and all the associated burdens that brings.

Access to local **support services** was also identified by numerous participants as an area for focussed improvement including:
- Linking in with a local support person or service
- Support for family members and carers

- Having someone to talk to besides family

Whilst this improvement was most commonly identified by rural participants, metropolitan participants saw this to be important too and as things that would have improved past or current experiences.

3.3.3. Improving information flow, communication and training

Table 15 summarises improvement ideas about **information flow, communication** and **training** for health professionals.

Table 15: Improvement ideas - Information flow, communication and training

Improvement ideas	Frequency
Improved information flow	8
Clear / open communication within and between providers	8
Streamline paperwork	5
Patient held record or similar	4
Training health professionals to give bad news	2
Training / support for local services	2
Timely access to results	2

Information flow, communication and training were seen to be important areas for improvement with a particular emphasis on the following:
- Improved information flow between services – *"They would all work together and that would be wonderful."*
- Clear and open communication between providers and with the person with cancer, their carers and families. This extended to creating open lines of communication between specialist and local providers such as GPs to enable optimal management of symptoms during active treatment and access to specialist advice when needed
- Training to support local skill development and service provision
- Communication skills training for health professionals.

Other improvement ideas included:
- Metropolitan services increasing awareness of issues for people from rural areas affected by cancer including distance and the many burdens of travel
- Attention to the environment and or facilities

4. Guiding key CanNET Victoria initiatives

This section of the report looks specifically at feedback from participants about the four CanNET priority areas. These areas were primarily explored in the group meetings, with interest in consumer participation also being discussed in individual interviews.

4.1. Consumer participation

"Who advocates for those who can't advocate for themselves?"

The population who participated in either the meetings or interviews noted they were keen to participate in order to improve services and experiences for themselves and others. **To date, 71 people have consented for their contact details and background information about their experience with cancer to be included in a consumer participation register for CanNET Victoria, Hume RICS and/or NEMICS (see 2.4.4 for a description of the registration process)**. Most of those currently on the register are individuals, but some are support group coordinators or other community or health service providers who wished to register in order to act as a conduit to a broader group of interested people.

In terms of being involved in future consumer participation projects around cancer service improvement, in the first instance participants were keen to hear of the outcomes of this current Project. However there was some difficulty in participants articulating specific preferences for other consumer participation opportunities without the detail of what might be planned and how it might evolve.

There was strong interest in mechanisms that would assist consumers (those with cancer and carers) to be more actively involved in their care and decision-making and to gain additional support including:
- Education and information to support consumer involvement in their own care and in navigating the system
- Individual and peer support for consumers
- Building on existing community support networks.

Participants also identified the need to create opportunities to tell their stories in order to guide future service improvement.

"You need a vehicle where you could pull cancer survivors together and get them to tell their stories and say to them in light of your circumstances 'what can we do to make it better?' "

A range of ways was identified in which consumers could provide input into service improvement initiatives including forums, surveys, and via the internet or existing support groups. In addition to this, participants highlighted the importance of approaches that are accessible in terms of time with an emphasis on participation opportunities outside of usual working hours.

There was strong interest from most participants in being informed about future opportunities for consumer participation. In addition, a smaller number of participants clearly had a range of advocacy and communication skills and interested in involvement in 'a whole of system' approach to service improvement. These participants potentially

may play important roles in the next stage of the CanNET consumer participation strategy.

One participant in particular clearly identified that while specific services were excellent the health system is very complex and trying to navigate the system was extremely challenging.

"The services were excellent really, but the system – there is so much complexity – dealing with that is what knocks you down dreadfully and you have to chase up for everything."

Taking a systems view, this participant described a constant sense of a 'chase' across a number of components of care:

- The **discovery chase** to gain a diagnosis
- The **money chase** to gain an understanding of service costs and billing and rebate systems
- The **treatment chase** focuses on what treatment will be provided where and how to access these services
- The **paper chase** identified the gaps in information across the system between individual services and providers, which the person with cancer or carer may need to fill
- The **help chase** focuses on where and when the person with cancer and carer can access help
- The **survival chase** focuses on how to survive through the system and after treatment or bereavement.

Finally service provider engagement in the consumer consultation processes reflects a level of interest in service development and in supporting future approaches to consumer participation that is very positive.

4.2. Services directory development

There was clear support for the development of a Services Directory as a crucial resource to assist people with cancer, their carers, family members and broader support networks to better navigate through their cancer journey. Responses particularly emphasised the importance of information about local services and practical supports. In the instance that services are not available locally, information about the most accessible alternatives was considered important.

Practical information topics (building upon those outlined in section 3.3.1) included:

- Support for travel including transport and accommodation options
- Financial assistance including carers' payment and assistance, other Centrelink benefits and travel costs
- Support within the home including home help, meals on wheels and respite services
- Specific services including community support services and groups, allied health services, palliative care
- Support for accessing specific resources such as prostheses, wigs, pressure garments and aids to support daily living.

"You just need a pamphlet saying who can I call for this, this, or this."

"You need a book that says where you can go to, what is claimable, who to go and see, who you can ring."

Specific information required about the various services included in a directory was cited as:

- What they provide
- Where and how you might access the service
- When you might need this service
- Associated costs.

Finally in terms of the content of the service directory, participants identified that it would be useful if the services directory also provided information about cancer itself, treatments and side effects. Given the range of information that is available, this might be best undertaken through ensuring the service directory included information and links to services such as the Cancer Council of Victoria's Cancer Information and Support Service.

Suggestions on the format of the services directory included:

- Web based
- Paper / hard copy
- Telephone based

In addition to this, participants also highlighted the importance of early accessibility of the services directory, for not only people with cancer but also carers and family.

"You need this information before you get to your treatment."

The services directory also needed to be accessible for people who are in or out of the system and to those people who have more limited English skills .

Finally participants highlighted the importance of promoting the services directory widely through GPs, community health services, libraries and other community services.

"The services directory needs to be distributed in country areas and tells you where to go."

4.3.   Improving skills and support for health professionals

The skills and confidence of local providers was raised as a key issue and reflected the need for health care providers in rural areas to be a *'jack of all trades'*. Specific areas for focus for health professional education to facilitate optimal local care included:

- Keeping up to date with the latest developments in cancer care
- Knowing how to provide support if a person is sick in between or after chemotherapy / hospitalisation
- Training to assist with pain management
- Specialist nursing skills for the provision of chemotherapy, wound care and port or PICC management
- Training for pathology providers in accessing difficult veins
- Providing access to information and to specialist providers to support local care provision and troubleshooting as required – *"recognising limitations and having back-up in place as needed."*

- Education about the impact of a cancer diagnosis to better enable local services to provide support
- Education / training for generalist providers such as counsellors, allied health professionals about cancer
- Regular ongoing training and support for all local health professionals.

In addition to this, other areas of focus that were raised as a focus for training of generalist and specialist service providers included:
- Communication skills training
- Providing people with cancer with an opportunity to be heard
- Improving bedside manner
- Acknowledging cultural sensitivity
- Creating a safe and comfortable place for questions to be asked.

4.4. Multidisciplinary care

Participants were asked if they had heard of the term multidisciplinary care. Whilst many participants were not familiar with the term, upon describing what multidisciplinary care is and what it involves, numerous people said that they were aware of this process taking place. In some cases, participants were actually present within the multidisciplinary team meeting, where their case was discussed; other participants stated that they had to consented for their case to be discussed in these meetings.

The concept and practice of multidisciplinary care was described and was supported as a valuable mechanism for care by all participants. Some participants saw it as a way of improving continuity and consistency, whilst other suggested that video conferencing may help to support regular multidisciplinary care meetings within regional and rural Victoria.

5. Informing CanNET Victoria – key directions

This report reflects the views and perspectives of 128 people affected by cancer living in the Hume RICS and NEMICS regions and a small number of service providers. These consultations have represented a key step in informing areas for focus for the remainder of the CanNET Victoria project including:

- The development of a successful and sustainable consumer participation strategy for the future
- Priority areas for service improvement.

5.1. Consumer participation in CanNET Victoria – a strategy

There is an opportunity to develop a robust consumer participation model that will provide both short-term and long-term gains for consumers, health services and the health system overall given:

- the evidence from the literature that short-term project based consumer participation for specific projects (such as CanNET) is not an effective approach for long-term and sustainable consumer involvement
- the level of interest generated in further consumer participation opportunities through this consultation
- the inter-connection and shared goals and agendas between CanNET Victoria, the Hume RICS and NEMICS
- the potential for CanNET Victoria to provide the initial impetus for the consumer participation strategy and for Hume RICS and NEMICS to support the strategy in an ongoing way

The recommended consumer participation strategy therefore builds on the drivers and resources within CanNET Victoria to achieve some specific short-term gains but also to develop the framework and strategic directions that can be integrated into and sustained through the Hume RICS and NEMICS.
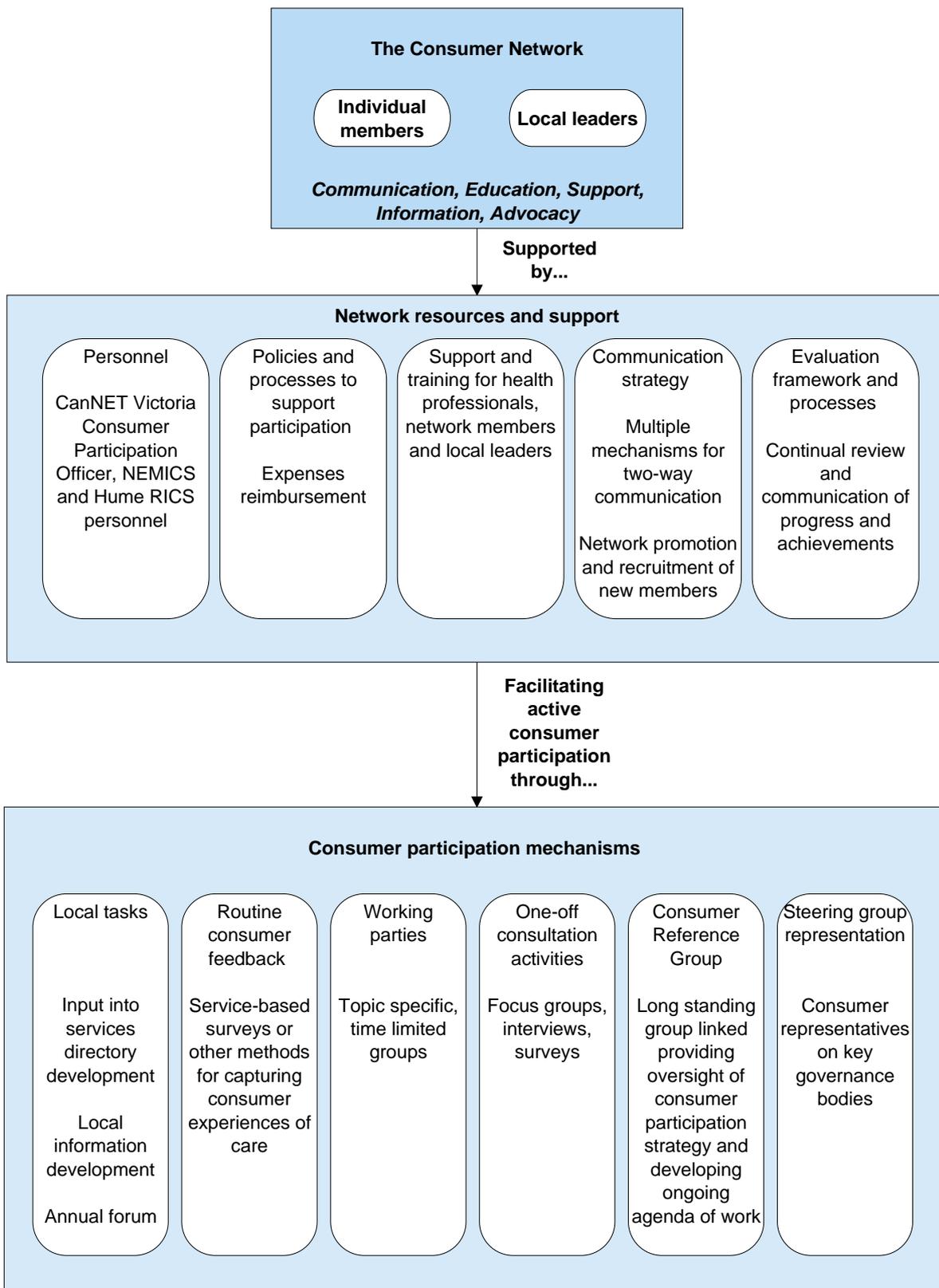
The consumer consultation findings identify a range of supportive care issues that are of particular interest for consumers. These consumer findings and interests compliment the future DHS directions for enhancing the provision of supportive care for those affected by cancer, underpinned by a consumer participation approach. These directions therefore provide an important opportunity to optimise active consumer participation within CanNET, Hume RICS and NEMICS.

The key elements of the recommended consumer participation strategy are:

- The development of a strong consumer network that:
  - draws in members from diverse backgrounds and interests
  - facilitates information and communication flow
  - provides a vehicle for information sharing, education, support and advocacy that optimises consumer involvement in their individual care as well as at a service and system level (drawing upon key directions outlined in section 1 of this report)
- A flexible approach that provides a range of mechanisms for involvement that consumers may choose to contribute to as they wish
- The development of a robust framework for consumer participation with clear structures and processes that will be sustainable.

Key elements of the proposed consumer participation strategy are illustrated in Figure 1.

Figure 1: CanNET Victoria consumer participation strategy – key elements

The Consumer Network

Individual members

Local leaders

Communication, Education, Support, Information, Advocacy

Supported by...

Network resources and support

Personnel	Policies and processes to support participation	Support and training for health professionals, network members and local leaders	Communication strategy	Evaluation framework and processes
CanNET Victoria Consumer Participation Officer, NEMICS and Hume RICS personnel	Expenses reimbursement		Multiple mechanisms for two-way communication	Continual review and communication of progress and achievements
			Network promotion and recruitment of new members	

Facilitating active consumer participation through...

Consumer participation mechanisms

Local tasks	Routine consumer feedback	Working parties	One-off consultation activities	Consumer Reference Group	Steering group representation
Input into services directory development	Service-based surveys or other methods for capturing consumer experiences of care	Topic specific, time limited groups	Focus groups, interviews, surveys	Long standing group linked providing oversight of consumer participation strategy and developing ongoing agenda of work	Consumer representatives on key governance bodies
Local information development					
Annual forum					

The longer term benefits of the successful adoption of this strategy include the availability of a strong and committed consumer voice within the Hume region that can effectively work with service providers and be mobilised to actively advocate for service improvements and additional resources to funding bodies.

Each of the key elements of this model are further described in the sections below.

5.1.1.　The 'Consumer Network'

The development of a strong consumer network will bring together anyone with an interest in improving cancer services at an individual, service or system level. This network will include a register of interested people and will underpin all consumer participation work and be a core resource for a range of activities.

The **key features** of the model are as follows:

Membership will include all interested parties including support group members, the current consumers who have registered their interest, other individuals, and service providers / community representatives, as appropriate. It is essential that the network is actively promoted and attracts new participants over time.

The **role** of the network will be to **facilitate communication, information, support and advocacy** at the individual, project / program, service and system level.

Flexible communication that enables 'members' to participate in the ways that they wish and facilitates access to communication using a range of mediums (eg electronic, hard-copy and use of the media outlets such as local newspapers, community posters).

The development and pro-active use of a **regular communication** mechanism (eg a newsletter) that:
- Provides information and educational updates about specific cancer issues, services and programs as well as progress in particular service improvement initiatives
- Offers tips for managing key symptoms and issues based on consumer experiences (Box 4)
- Uses consumer stories to facilitate informal peer support
- Develops an interactive approach that enables consumers to provide input eg calls for stories or tips for a specific issue or calls for responses to key questions, that would help to guide service improvement activities.

BOX 4. SHARING CONSUMER STORIES AND TIPS - examples

On telling children…
"We sat down with our kids and said this is what is happening – and it going to be crap, your mother may turn into a 'psychopath' but we are going to cope.

We tell them everything and told them that there would be no surprises. Or if there were they would be surprises for us all."

Mother of two young children aged 10 and 15 years

On things that have helped people to cope…
"I have dealt with this cancer by having a calico bag hanging on the back of my door – I call it my "shit bag" – mentally I put everything that I can into the bag – I put my grief in there and my anger that I won't see another grandchild."

Woman in her 60s with an aggressive cancer

The development of **local 'leaders'** to play a key contact role and coordination within local communities, facilitate informal conversations on specific issues, or organise local forums as required.

This active Network would require initial and ongoing resourcing. Once established the Network will support a range of mechanisms to facilitate further consumer participation and advocacy work.

5.1.2. Supporting the Consumer Network and consumer participation

A series of key resources and supports have been identified that will be important to have in place to facilitate the successful implementation of this consumer participation strategy and to optimise its ongoing functioning and value to both network participants and cancer services.

Each key resource / support mechanism is described below:

Personnel: The CanNET Victoria Consumer Participation Officer working with colleagues at Hume RICS and NEMICS will play a central role in:
- establishing the recommended consumer participation model, network and underpinning policies and protocols
- inviting network members to participate in participation activities
- planning and coordinating network activities
- supporting and resourcing network members through the network newsletter and other communication mechanisms
- disseminating information about the network amongst health and community networks to facilitate continual promotion and recruitment of new network members
- training and support for network members, local leaders and health service providers
- supporting consumers in agreed mechanisms eg a specific working party
- identifying opportunities for consumer participation in key activities being undertaken through CanNET Victoria, Hume RICS and NEMICS.

Policies and protocols to support participation: A policy and protocol (ideally consistent across CanNET Victoria, NEMICS and Hume RICS) would need to be developed to guide reimbursement of expenses by consumer participants who participate in specific activities. This would need to consider sitting fees, travel expenses, parking and childcare costs.

Support and training for health professionals, network members and local leaders: Drawing upon existing training programs developed to support consumer participation (eg. Cancer Voices, Health Issues Centre), a strategy would be developed and implemented that supports and provides education and skill development around consumer participation for all parties involved. This would emphasise mechanisms for mentoring, support and information provision.

Communication strategy: A communication strategy would be developed that would outline a series of mechanisms that would enable two-way communication and linkages between network members and communication of key information into working party, consumer reference group, steering groups or other key forums for further

consideration. A part of this strategy would be the development of resources and mechanisms for the ongoing promotion of the consumer network and the recruitment of new members.

Evaluation framework and processes: Given the paucity of evaluation data around consumer participation, a focus on putting mechanisms in place to capture key activities undertaken and to support the continual review and improvement of the consumer participation strategy would ideally be developed. A key element of this approach would be a focus on the dissemination of information relating to achievements and lessons learned to the range of stakeholders in cancer care and the network itself.

5.1.3.   The consumer network — facilitating consumer participation

The consumer network, once established will provide an ongoing resource for CanNET in the short-term and Hume RICS, NEMICS and individual services in the longer term. The Network will facilitate consumer involvement in a range of service improvement activities through a range of formal and informal mechanisms as previously illustrated in Figure 1.

The following describes some of the mechanisms that may be used in more detail. In addition, different mechanisms may be used to gain input into the same activity eg one-off consultation activities may be conducted to inform a working party.

Locally based tasks. This includes a range of work that can be undertaken by the local leader with interested Network members. Such tasks could include:
* the identification of local services to be added to a regional service directory
* gaining consumer stories for specific issues
* informal conversations about 'hot topics' or key issues.

Some of the tasks will have a very short time frame whereas others may require some ongoing work over a longer time.

The development and implementation of annual **'consumer forums'** across the Hume and North Eastern Metropolitan regions. These forums may be similar to those held within the context of the Project consultation and will provide an opportunity to:
* Offer local information and education sessions about cancer and cancer services
* Update consumers on progress on current service improvement initiatives
* Gain their input into other issues
* Elicit their perspectives on cancer care and future mechanisms and priorities for service improvement
* Attract new members to the consumer network.

One-off consultations. These would be aimed to gain consumer input into specific issues that would be then used to inform service improvement work. One-off consultations could include:
* low key mechanisms such as informal conversations as described above.
* more formal individual interviews or focus group discussions undertaken by a facilitator, interviewer or local network leader
* gaining individual feedback on the experience of care through a feedback survey conducted at a service level or through the network.

Working parties. These would be formed to gain input from consumers for a specific initiative for a clearly defined and relatively short period of time. The working parties would draw together consumers from across the region with an interest in the specific topic or service improvement area. Depending on the focus, working parties may also include service providers.

Formal meetings may be face-to-face or via teleconferencing and would be supplemented by other more informal communication mechanisms. Within the life of CanNET, a working party may be established to support the development of the service directory.

Consumer reference group. The purpose of a consumer reference group would be to address a broader range of consumer driven issues or service improvement activities over a longer period of time. For example a consumer reference group could have been established for a two year period to support the CanNET work or could be established in an ongoing way to support the work of the Hume RICS and NEMICS.

The consumer reference group would have links with any steering committee / advisory group through the participation of a minimum of two consumer reference group members as consumer representatives on the steering committee.

Steering committee or advisory groups. These steering groups or advisory committees include existing mechanisms in place for CanNET Victoria, Hume RICS and NEMICS and would include a minimum of two consumer representatives.

5.1.4. Implementing the consumer participation strategy

With a reasonable investment of both staffing and related infrastructure support in the first 12 to 18 months the following outcomes could be expected:
1. A consumer participation strategy will be endorsed and implemented

2. The CanNET Victoria Consumer Participation Officer will be appointed and and key personnel within NEMICS and Hume RICS will be identified to work as the implementation team

3. The findings of this Project will be clearly communicated to current participants, the community and other key stakeholders

4. Policies, processes and protocols to guide consumer participation will be developed and agreed

5. The overall consumer network will be established and its membership will have grown substantially

6. Support and training needs of network members, local leaders and service providers working with consumers will be clearly identified and addressed

7. The communication strategy for the consumer network will be well established

8. An evaluation framework will have been developed and key evaluation tasks undertaken to review progress and achievements to date

9. Consumers will have been actively involved in a range of short term priority activities including the development of the service directory

10. Consumers will be active participants in other service improvement activities

11. One annual round of consumer forums will have been held across the Hume and NEMICS regions

12. There will be a clear understanding of the level of ongoing resources required to support a sustainable consumer participation model for the future and a strategy in place to ensure the smooth transition to full oversight by NEMICS and Hume RICS.

In the first 12 to 18 months, it is considered that a full time Consumer Participation Officer position would need to be appointed to provide a significant resource to develop and build the consumer network and the related components of the strategy. Once established and with the collaborative approach proposed with NEMICS and Hume RICS, this role would shift to a part-time load. Maintaining a focussed human resource or resources with responsibility and sufficient hours to continue to support the strategy over time will be crucial to its success.

An additional budget will be required to support implementation of the reimbursement policy as well as to develop key communication mechanisms, promotional materials and to support participation activities such as local forums and evaluation components.

5.2. Consumer voices guiding CanNET Victoria activities

In addition to the consumer participation strategy itself, a series of key areas of focus across the CanNET Victoria priority areas and service improvement ideas have been identified in this project that require further consideration.

A series of focussed areas for improvement have emerged strongly from these consultations including:

- The importance of the development of a robust, accessible service directory including local, regional and statewide information on a whole range of practical and support services that people affected by cancer, their carers and family members may access

- The inclusion of information in the services directory or other forms that addresses key challenges raised such as:
  - What to expect
  - What questions to ask
  - What happens next
  - Common tests and treatments – what they involve
  - Information about specific cancer types and treatments
  Ideally this would draw from existing sources rather than duplicate resources already available

- Mechanisms for the active engagement of local GPs and other community providers as key members of an extended cancer care team

- The need to further review and develop consistent and transparent policies and practices in relation to treatment costs, billing policies and payment options for people without the means to pay up front for their treatment

- The development of a series of initiatives to enhance local access to care and skill development for local service providers to enhance support and quality care as close to home as possible. This may include:
    - o Rolling out an education program for district nurses (or other appropriately credentialled local providers) to facilitate port management and symptom identification and referral practices for people when at home in between chemotherapy treatments
    - o The provision of information for local GPs about the cancer that their patient has developed, its treatment, side effects and how they can support the person with cancer and their families to manage
    - o Exploring the range of local services that may provide pathology, radiology or other key services to facilitate local access for people with cancer where possible

It is recommended that the CanNET steering group consider the findings presented in this report and consider the endorsement of the proposed consumer participation strategy and focussed work in the areas summarised above.

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